



## Complete Summary

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### **GUIDELINE TITLE**

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 1-2: any cancer experience.

### **BIBLIOGRAPHIC SOURCE(S)**

Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 1-2: any cancer experience. Bethesda (MD): Children's Oncology Group; 2006 Mar. 4 p. [50 references]

### **GUIDELINE STATUS**

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

## COMPLETE SUMMARY CONTENT

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## SCOPE

### **DISEASE/CONDITION(S)**

Late effects, including psychosocial and mental health disorders, resulting from therapeutic exposures used during treatment for pediatric malignancies

**Note:** These guidelines are intended for use beginning two or more years following the completion of cancer therapy, and provide a framework for ongoing late effects monitoring in childhood cancer survivors; however, these guidelines

are not intended to provide guidance for follow-up of the pediatric cancer survivor's primary disease.

### **GUIDELINE CATEGORY**

Evaluation  
Management  
Prevention  
Screening

### **CLINICAL SPECIALTY**

Family Practice  
Internal Medicine  
Obstetrics and Gynecology  
Oncology  
Pediatrics  
Psychiatry  
Psychology

### **INTENDED USERS**

Advanced Practice Nurses  
Nurses  
Physician Assistants  
Physicians  
Psychologists/Non-physician Behavioral Health Clinicians  
Social Workers

### **GUIDELINE OBJECTIVE(S)**

- To provide recommendations for screening and management of late effects in survivors of pediatric malignancies
- To increase quality of life and decrease complication-related healthcare costs for pediatric cancer survivors by providing standardized and enhanced follow-up care throughout the life-span that (a) promotes healthy lifestyles, (b) provides for ongoing monitoring of health status, (c) facilitates early identification of late effects, and (d) provides timely intervention for late effects

### **TARGET POPULATION**

Asymptomatic survivors of childhood, adolescent, or young adult cancers who present for routine exposure-related medical follow-up

### **INTERVENTIONS AND PRACTICES CONSIDERED**

Thorough history and physical examination, including psychosocial assessment, and targeted screening evaluations

### **MAJOR OUTCOMES CONSIDERED**

Not stated

## METHODOLOGY

### METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)  
Hand-searches of Published Literature (Secondary Sources)  
Searches of Electronic Databases

### DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Pertinent information from the published medical literature over the past 20 years (updated as of October 2005) was retrieved and reviewed during the development and updating of these guidelines. For each therapeutic exposure, a complete search was performed via MEDLINE (National Library of Medicine, Bethesda, MD). Keywords included "childhood cancer therapy," "complications," and "late effects," combined with keywords for each therapeutic exposure. References from the bibliographies of selected articles were used to broaden the search.

### NUMBER OF SOURCE DOCUMENTS

Not stated

### METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus (Committee)  
Weighting According to a Rating Scheme (Scheme Given)

### RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

"High-level evidence" (recommendation category 1) was defined as evidence derived from high quality case control or cohort studies.

"Lower-level evidence" (recommendation categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series, and clinical experience.

### METHODS USED TO ANALYZE THE EVIDENCE

Systematic Review with Evidence Tables

### DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

The guidelines were scored by the multidisciplinary panel of experts using a modified version of the National Criteria: Comprehensive Cancer Network "Categories of Consensus" system. Each score reflects the expert panel's assessment of the strength of data from the literature linking a specific late effect with a therapeutic exposure, coupled with an assessment of the appropriateness

of the screening recommendation based on the expert panel's collective clinical experience. "High-level evidence" (category 1) was defined as evidence derived from high quality case control or cohort studies. "Lower-level evidence" (categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series and clinical experience. Rather than submitting recommendations representing major disagreements, items scored as "Category 3" were either deleted or revised by the panel of experts to provide at least a "Category 2B" score for all recommendations included in the guidelines.

## **METHODS USED TO FORMULATE THE RECOMMENDATIONS**

Expert Consensus

### **DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS**

In 2002, the leadership of the Children's Oncology Group Late Effects Committee and Nursing Discipline appointed a 7-member task force, with representation from the Late Effects Committee, Nursing Discipline, and Patient Advocacy Committee. The task force was convened to review and summarize the medical literature and develop a draft of clinical practice guidelines to direct long-term follow-up care for pediatric cancer survivors. The task force followed a modified version of the guideline development process established by the National Comprehensive Cancer Network (NCCN), integrating available literature with expert opinion using reiterative feedback loops.

The original draft went through several iterations within the task force prior to initial review. Multidisciplinary experts in the field, including nurses, physicians (pediatric oncologists and other subspecialists), patient advocates, behavioral specialists, and other healthcare professionals, were then recruited by the task force to provide an extensive, targeted review of the draft, including focused review of selected guideline sections. Revisions were made based on these recommendations. The revised draft was then sent out to additional multidisciplinary experts for further review. A total of 62 individuals participated in the review process. The guidelines subsequently underwent comprehensive review and scoring by a panel of experts in the late effects of pediatric malignancies, comprised of multidisciplinary representatives from the COG Late Effects Committee.

### **Revisions**

In order to keep the guidelines current and clinically meaningful, the COG Late Effects Committee organized 18 multi-disciplinary task forces in March 2004. These task forces were charged with the responsibility for monitoring the medical literature in regard to specific system-related clinical topics relevant to the guidelines (e.g., cardiovascular, neurocognitive, fertility/reproductive), providing periodic reports to the Late Effects Committee, and recommending revisions to the guidelines and their associated health education materials and references (including the addition of therapeutic exposures) as new information became available. Task force members were assigned according to their respective areas of expertise and clinical interest. A list of these task forces and their membership is included in the "Contributors" section of the original guideline document. The

revisions incorporated into the current release of these guidelines (Version 2.0 – March 2006) reflect the contributions and recommendations of these task forces.

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score (see "Rating Scheme for the Strength of the Evidence"). Proposed revisions that were rejected by the expert panel were returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel. A total of 34 sections and 9 Health Links were added to Version 2.0 of these guidelines.

## **RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS**

Each score relates to the strength of the association of the identified late effect with the specific therapeutic exposure based on current literature, and is coupled with a recommendation for periodic health screening based on the collective clinical experience of the panel of experts. This is due to the fact that there are no randomized clinical trials (and none forthcoming in the foreseeable future) on which to base recommendations for periodic screening evaluations in this population; therefore, the guidelines should not be misconstrued as representing conventional "evidence-based clinical practice guidelines" or "standards of care".

Each item was scored based on the level of evidence currently available to support it. Scores were assigned according to a modified version of the National Comprehensive Cancer Network "Categories of Consensus," as follows:

1 There is uniform consensus of the panel that (1) there is high-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2A There is uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2B There is non-uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

3 There is major disagreement that the recommendation is appropriate.

## **COST ANALYSIS**

A formal cost analysis was not performed and published cost analyses were not reviewed.

## **METHOD OF GUIDELINE VALIDATION**

External Peer Review  
Internal Peer Review

## DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The initial version of the guidelines (Version 1.0 – Children's Oncology Group Late Effects Screening Guidelines) was released to the Children's Oncology Group (COG) membership in March 2003 for a six-month trial period. This allowed for initial feedback from the COG membership, resulting in additional review and revision of the guidelines by the Late Effects Committee prior to public release.

### Revisions

All revisions proposed by the task forces were evaluated by a panel of experts, and if accepted, assigned a score (see "Rating Scheme for the Strength of the Evidence"). Proposed revisions that were rejected by the expert panel were returned with explanation to the relevant task force chair. If desired, task force chairs were given an opportunity to respond by providing additional justification and resubmitting the rejected task force recommendation(s) for further consideration by the expert panel.

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

Grades of recommendations (1, 2A, 2B, 3) are defined at the end of the "Major Recommendations" field.

**Note from the Children's Oncology Group and the National Guideline Clearinghouse (NGC):** The *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* (COG LTFU) are organized according to therapeutic exposures; this guideline has been divided into individual summaries. In addition to the current summary, the following are available:

- [Sections 3–5: Blood/Serum Products](#)
- [Sections 6–37: Chemotherapy](#)
- [Sections 38–91: Radiation](#)
- [Sections 92–106: Hematopoietic Cell Transplant](#)
- [Sections 107–132: Surgery](#)
- [Sections 133–136: Other Therapeutic Modalities](#)
- [Sections 137–146: Cancer and General Health Screening](#)

In order to accurately derive individualized screening recommendations for a specific childhood cancer survivor using this guideline, see "Using the COG LTFU Guidelines to Develop Individualized Screening Recommendations" in the [original guideline document](#). (Note: For ease of use, a Patient-Specific Guideline Identification Tool has been developed to streamline the process and is included in [Appendix I](#) of the original guideline document.)

### Guideline Organization

The *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* are organized according to therapeutic exposures, arranged by column as follows:

|  |   |
|--|---|
| <b>System</b>  | Body system (e.g., auditory, musculoskeletal) most relevant to each guideline section.  |
| <b>Score</b>   | Score assigned by expert panel representing the strength of data from the literature linking a specific late effect with a therapeutic exposure coupled with an assessment of the appropriateness of the screening recommendation based on collective clinical experience.  |
| <b>Section Number</b>                                | Unique identifier for each guideline section corresponding with listing in Index.   |
| <b>Therapeutic Agent</b>                             | Therapeutic intervention for malignancy, including chemotherapy, radiation, surgery, blood/serum products, hematopoietic cell transplant, and other therapeutic modalities.   |
| <b>Risk Factors</b>                                  | Host factors (e.g., age, sex, race, genetic predisposition), treatment factors (e.g., cumulative dose of therapeutic agent, mode of administration, combinations of agents), medical conditions (e.g., pre-morbid or co-morbid conditions), and health behaviors (e.g., diet, smoking, alcohol use) that may increase risk of developing the complication.  |
| <b>Highest Risk Factors</b>                          | Conditions (host factors, treatment factors, medical conditions and/or health behaviors) associated with the highest risk for developing the complication.  |
| <b>Periodic Evaluations</b>                          | Recommended screening evaluations, including health history, physical examination, laboratory evaluation, imaging, and psychosocial assessment. Recommendation for minimum frequency of periodic evaluations is based on risk factors and magnitude of risk, as supported by the medical literature and/or the combined clinical experience of the reviewers and panel of experts.  |
| <b>Health Counseling/<br/>Further Considerations</b> | <p><b>Health Links:</b> Health education materials developed specifically to accompany these guidelines. Title(s) of Health Link(s) relevant to each guideline section are referenced in this column. Health Link documents are included in <a href="#">Appendix II</a> of the original guideline document.</p> <p><b>Counseling:</b> Suggested patient counseling regarding measures to prevent/reduce risk or promote early detection of the potential treatment complication.</p> <p><b>Resources:</b> See the original guideline document for lists of books and web sites that may provide the clinician with additional relevant information.</p> <p><b>Considerations for Further Testing and Intervention:</b> Recommendations for further diagnostic evaluations beyond minimum screening for individuals with positive screening tests, recommendations for consultation and/or referral, and</p> |

recommendations for management of exacerbating or predisposing conditions.

## References

References are listed immediately following each guideline section in the original guideline document. Included are medical citations that provide evidence for the association of the therapeutic intervention with the specific treatment complication and/or evaluation of predisposing risk factors. In addition, some general review articles have been included in the Reference section of the original guideline document for clinician convenience.

**Note:** See the end of the "Major Recommendations" field for explanations of [abbreviations](#) included in the summary.

**System = Psychosocial**  
**Score = 2A**

| Sec # | Therapeutic Agent(s)  | Potential Late Effects   | Risk Factors  | Highest Risk Factors  | Periodic Evaluation   | Health Counseling Further Considerations  |
|-------|---|--|---|---|---|---|
| 1     | <b>Any Cancer Experience</b><br><br><b>Info Link:</b><br>The Children's Oncology Group Follow-Up Guidelines apply to patients who have been off therapy for a minimum of 2 years. | <b>Psychosocial Disorders</b><br>Social withdrawal<br>Educational problems       | <b>Host Factors</b><br>Female sex<br>Family history of depression, anxiety or mental illness<br><br><b>Social Factors</b><br>Lower household income<br>Lower educational achievement<br><br><b>Treatment Factors</b><br>HCT | <b>Host Factors</b><br>CNS tumor<br>CNS-directed therapy<br>Premorbid learning or emotional difficulties<br><br><b>Social Factors</b><br>Failure to graduate from high school | <b>History Psychosocial assessment, with attention to:</b> <ul style="list-style-type: none"> <li>Educational and/or vocational progress</li> <li>Depression</li> <li>Anxiety</li> <li>Post-traumatic stress</li> <li>Social withdrawal</li> </ul> (Yearly) | <b>Health Link</b><br><b>See "Patient Resources" field</b><br><br>Introduction<br>Long-Term Follow-Up<br>Emotional Issues<br>Educational Issues<br>Chronic Pain after Childhood Cancer<br><br><b>Resources</b><br>See the original guideline document for list of books and web sites that may provide clinician with additional relevant information |
|       |   | <b>Mental Health Disorders</b><br>Depression<br>Anxiety<br>Post-traumatic stress | <b>Host Factors</b><br>Female sex<br>Family history of depression, anxiety, or mental illness<br><br><b>Social Factors</b>  | <b>Host Factors</b><br>CNS tumor<br>CNS-directed therapy<br>Premorbid learning or emotional   |   |   |



| Sec # | Therapeutic Agent(s) | Potential Late Effects   | Risk Factors  | Highest Risk Factors  | Periodic Evaluation | Health Counseling and Further Considerations   |
|-------|----------------------|--|---|---|---------------------|--|
|       |                      |  | Lower household income<br>Lower educational achievement<br><br><b>Treatment Factors</b><br>HCT  | difficulties<br><br><b>Social Factors</b><br>Failure to graduate from high school                           |                     | <b>Considerations for Further Testing and Intervention</b><br>Consider psychological consultation for patients with emotional difficulties related to cancer experience, including physical deformities or chronic disabilities. Consider appropriate psychotropic medications. Consider evaluation of parent for post-traumatic stress syndrome. Consider social work consultation. Refer as indicated to school liaison or community cancer center (psychologist, social worker, school counselor) to facilitate acquisition of educational resources. Screen for physical sources of fatigue, such as anemia, |
|       |                      | <b>Risky Behaviors</b><br>Behaviors known to increase the likelihood of subsequent illness or injury | <b>Social Factors</b><br>Lower household income   | <b>Host Factors</b><br>Older age at diagnosis<br><br><b>Social Factors</b><br>Lower educational achievement |                     |  |
|       |                      | <b>Psychosocial Disability due to Pain</b>   | <b>Treatment Factors</b><br>Amputation<br>Radiation to bone/joint<br>Limb-sparing surgery<br>Vincristine exposure<br><br><b>Medical Conditions</b><br>Osteonecrosis | <b>Host Factors</b><br>CNS tumor<br>Hodgkin lymphoma  |                     |  |
|       |                      | <b>Fatigue</b>   | <b>Host Factors</b><br>Female sex<br>Depression<br>Obesity<br><br><b>Social Factors</b><br>Unemployment   | <b>Treatment Factors</b><br>Pulmonary radiation   |                     |  |

| Sec # | Therapeutic Agent(s) | Potential Late Effects | Risk Factors | Highest Risk Factors | Periodic Evaluation | Health Counseling Further Considerations  |
|-------|----------------------|------------------------|--------------|----------------------|---------------------|---|
|       |                      |                        |              |                      |                     | sleep disturbance<br>nutritional deficiencies<br>cardiomyopathy<br>pulmonary fibrosis,<br>hypothyroidism<br>or other endocrinopathies |

**Note:** See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

**System = Psychosocial  
Score = 2A**

| Sec # | Therapeutic Agent(s)         | Potential Late Effects                                | Risk Factors   | Highest Risk Factors | Periodic Evaluation  | Health Counseling Further Considerations  |
|-------|------------------------------|---|--|----------------------|--|---|
| 2     | <b>Any Cancer Experience</b> | <b>Limitations in healthcare and insurance access</b> | <b>Social Factors</b><br>Lower household income<br>Lower educational achievement |                      | <b>History</b><br><br><b>Psychosocial assessment, with attention to healthcare insurance and access (Yearly)</b> | <b>Health Links</b><br><br><b>See "Patient Resources" field</b><br>Finding Healthcare<br><br><b>Considerations for Further Testing and Intervention</b><br>Social work consultation |

**Note:** See a list of [Abbreviations](#) at the end of the "Major Recommendations" field.

### Abbreviations

CNS, central nervous system; HCT, hematopoietic cell transplant

### Definitions:

## **Explanation of Scoring for the Long-Term Follow-Up Guidelines**

Each item was scored based on the level of evidence currently available to support it. Scores were assigned according to a modified version of the National Comprehensive Cancer Network "Categories of Consensus," as follows:

1 There is uniform consensus of the panel that (1) there is high-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2A There is uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

2B There is non-uniform consensus of the panel that (1) there is lower-level evidence linking the late effect with the therapeutic exposure, and (2) the screening recommendation is appropriate based on the collective clinical experience of panel members.

3 There is major disagreement that the recommendation is appropriate.

## **Rating Scheme for the Strength of the Evidence**

"High-level evidence" (recommendation category 1) was defined as evidence derived from high quality case control or cohort studies.

"Lower-level evidence" (recommendation categories 2A and 2B) was defined as evidence derived from non-analytic studies, case reports, case series, and clinical experience.

## **CLINICAL ALGORITHM(S)**

None provided

## **EVIDENCE SUPPORTING THE RECOMMENDATIONS**

### **TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS**

The type of supporting evidence is identified and graded for each recommendation (see "Major Recommendations")

Although several well-conducted studies on large populations of childhood cancer survivors have demonstrated associations between specific exposures and late effects, the size of the survivor population and the rate of occurrence of late effects does not allow for clinical studies that would assess the impact of screening recommendations on the morbidity and mortality associated with the late effect. Therefore, scoring of each exposure reflects the expert panel's assessment of the level of literature support linking the therapeutic exposure with

the late effect coupled with an assessment of the appropriateness of the recommended screening modality in identifying the potential late effect based on the panel's collective clinical experience.

## **BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS**

### **POTENTIAL BENEFITS**

Potential benefits of implementing these guidelines into clinical practice include earlier identification of and intervention for late onset therapy-related complications in this at-risk population, potentially reducing or ameliorating the impact of late complications on the health status of survivors. In addition, ongoing healthcare that promotes healthy lifestyle choices and provides ongoing monitoring of health status is important for all cancer survivors.

### **POTENTIAL HARMS**

Potential harms of guideline implementation include increased patient anxiety related to enhanced awareness of possible complications, as well as the potential for false-positive screening evaluations, leading to unnecessary further workup. In addition, costs of long-term follow-up care may be prohibitive for some patients, particularly those lacking health insurance, or those with insurance that does not cover the recommended screening evaluations.

## **QUALIFYING STATEMENTS**

### **QUALIFYING STATEMENTS**

- The information and contents of each document or series of documents made available by the Children's Oncology Group relating to late effects of cancer treatment and care or containing the title "Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers" or the title "Health Link," whether available in print or electronic format (including any digital format, e-mail transmission, or download from the website), shall be known hereinafter as "Informational Content." All Informational Content is for informational purpose only. The Informational Content is not intended to substitute for medical advice, medical care, diagnosis, or treatment obtained from a physician or healthcare provider.
- *To cancer patients (if children, their parents or legal guardians):* Please seek the advice of a physician or other qualified healthcare provider with any questions you may have regarding a medical condition and do not rely on the Informational Content. The Children's Oncology Group is a research organization and does not provide individualized medical care or treatment.
- *To physicians and other healthcare providers:* The Informational Content is not intended to replace your independent clinical judgment, medical advice, or to exclude other legitimate criteria for screening, health counseling, or intervention for specific complications of childhood cancer treatment. Neither is the Informational Content intended to exclude other reasonable alternative follow-up procedures. The Informational Content is provided as a courtesy, but not intended as a sole source of guidance in the evaluation of childhood cancer survivors. The Children's Oncology Group recognizes that specific

patient care decisions are the prerogative of the patient, family, and healthcare provider.

- While the Children's Oncology Group has made every attempt to assure that the Informational Content is accurate and complete as of the date of publication, no warranty or representation, express or implied, is made as to the accuracy, reliability, completeness, relevance, or timeliness of such Informational Content.
- No liability is assumed by the Children's Oncology Group or any affiliated party or member thereof for damage resulting from the use, review, or access of the Informational Content. You agree to the following terms of indemnification: (i) "Indemnified Parties" include authors and contributors to the Informational Content, all officers, directors, representatives, employees, agents, and members of the Children's Oncology Group and affiliated organizations; (ii) by using, reviewing, or accessing the Informational Content, you agree, at your own expense, to indemnify, defend and hold harmless Indemnified Parties from any and all losses, liabilities, or damages (including attorneys' fees and costs) resulting from any and all claims, causes of action, suits, proceedings, or demands related to or arising out of use, review or access of the Informational Content.
- Ultimately, as with all clinical guidelines, decisions regarding screening and clinical management for any specific patient should be individually tailored, taking into consideration the patient's treatment history, risk factors, co-morbidities, and lifestyle. These guidelines are therefore not intended to replace clinical judgment or to exclude other reasonable alternative follow-up procedures. The Children's Oncology Group recognizes that specific patient care decisions are the prerogative of the patient, family, and healthcare provider.

## **IMPLEMENTATION OF THE GUIDELINE**

### **DESCRIPTION OF IMPLEMENTATION STRATEGY**

Implementation of these guidelines is intended to standardize and enhance follow-up care provided to survivors of pediatric malignancies throughout the lifespan. Considerations in this regard include the practicality and efficiency of applying these broad guidelines in individual clinical situations. Studies to address guideline implementation and refinement are a top priority of the Children's Oncology Group (COG) Late Effects Committee, and proposals to study feasibility of guideline use in limited institutions are currently underway. Issues to be addressed include description of anticipated barriers to application of the recommendations in the guidelines and development of review criteria for measuring changes in care when the guidelines are implemented. Additional concerns surround the lack of current evidence establishing the efficacy of screening for late complications in pediatric cancer survivors. While most clinicians believe that ongoing surveillance for these late complications is important in order to allow for early detection and intervention for complications that may arise, development of studies addressing the efficacy of this approach is imperative in order to determine which screening modalities are optimal for asymptomatic survivors.

In addition, the clinical utility of this lengthy document has also been a top concern of the COG Late Effects Committee. While recognizing that the length and depth of these guidelines is important in order to provide clinically-relevant,

evidence-based recommendations and supporting health education materials, clinician time limitations and the effort required to identify the specific recommendations relevant to individual patients have been identified as barriers to their clinical application. Therefore, the COG Late Effects Committee is currently partnering with the Baylor School of Medicine in order to develop a web-based interface, known as "Passport for Care," that will generate individualized exposure-based recommendations from these guidelines in a clinician-focused format for ease of patient-specific application of the guidelines in the clinical setting. As additional information regarding implementation of the Passport for Care web-based interface becomes available, updates will be posted at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org).

## **IMPLEMENTATION TOOLS**

Chart Documentation/Checklists/Forms  
Patient Resources  
Resources

For information about [availability](#), see the "Availability of Companion Documents" and "Patient Resources" fields below.

## **INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES**

### **IOM CARE NEED**

Living with Illness  
Staying Healthy

### **IOM DOMAIN**

Effectiveness  
Patient-centeredness

## **IDENTIFYING INFORMATION AND AVAILABILITY**

### **BIBLIOGRAPHIC SOURCE(S)**

Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 1-2: any cancer experience. Bethesda (MD): Children's Oncology Group; 2006 Mar. 4 p. [50 references]

### **ADAPTATION**

Not applicable: The guideline was not adapted from another source.

### **DATE RELEASED**

2003 Sep (revised 2006 Mar)

**GUIDELINE DEVELOPER(S)**

Children's Oncology Group - Medical Specialty Society

**SOURCE(S) OF FUNDING**

This work was supported by the Children's Oncology Group grant U10 CA098543 from the National Cancer Institute.

**GUIDELINE COMMITTEE**

Children's Oncology Group Nursing Discipline and Late Effects Committee

**COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE**

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**FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST**

All Children's Oncology Group (COG) members have complied with the COG conflict of interest policy, which requires disclosure of any potential financial or other conflicting interests.

**GUIDELINE STATUS**

This is the current release of the guideline.

This guideline updates a previous version: Children's Oncology Group. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 1.2. 2004 Mar.

**GUIDELINE AVAILABILITY**

Electronic copies: Available in Portable Document Format (PDF) from the [Children's Oncology Group Web site](#).

## **AVAILABILITY OF COMPANION DOCUMENTS**

The following are available:

- Instructions for use. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 6 p.
- Introductory material. Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March. 9 p.
- Summary of cancer treatment. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March.
- Patient-specific guideline identification tool. Appendix I: Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Version 2.0. Children's Oncology Group. 2006 March.

Electronic copies: Available in Portable Document Format (PDF) from the [Children's Oncology Group Web site](#).

## **PATIENT RESOURCES**

In an effort led by the Nursing Clinical Practice Subcommittee, complementary patient education materials (*Health Links*) were developed and are available in Appendix II of the original guideline document. The following Health Links are relevant to this summary:

### **Section 1**

- [Introduction to Long-Term Follow-Up](#)
- [Emotional Issues](#)
- [Educational Issues](#)
- [Chronic Pain after Childhood Cancer](#)

### **Section 2**

- [Finding Healthcare](#)

Please note: This patient information is intended to provide health professionals with information to share with their patients to help them better understand their health and their diagnosed disorders. By providing access to this patient information, it is not the intention of NGC to provide specific medical advice for particular patients. Rather we urge patients and their representatives to review this material and then to consult with a licensed health professional for evaluation of treatment options suitable for them as well as for diagnosis and answers to their personal medical questions. This patient information has been derived and prepared from a guideline for health care professionals included on NGC by the authors or publishers of that original guideline. The patient information is not reviewed by NGC to establish whether or not it accurately reflects the original guideline's content.

## **NGC STATUS**



This NGC summary was completed by ECRI on May 4, 2007. The information was verified by the guideline developer on June 11, 2007.

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